Family experiences after parental cancer

Donofrio, Stacey Mavis

Chapter 6

Impacts of participant source on study results in psychosocial cancer research

SM Gazendam-Donofrio
WTA van der Graaf
HJ Hoekstra
A Visser
GA Huizinga
HBM van de Wiel
JEHM Hoekstra-Weebers

Submitted

Abstract

Background: To generalize results, the study sample must be representative of the population. Participants recruited from different sources may differ significantly in characteristics or functioning. This study explored to what extent participants in a psychosocial oncological study recruited through various channels can be considered equal.

Methods: Data from 207 cancer patients and family members approached by hospital staff to participate in a study (internally-recruited) was compared to data from 89 families who sought contact with the research team (externally-recruited).

Results: Internally-recruited families differed from externally-recruited: in internal families recurrence was more prevalent; martial relationship was shorter; there were fewer single-parent families; parents' educational level was lower; and children were older. The patients' functioning differed significantly on all 8 QOL subscales and intrusion and total stress response symptoms. Spouses differed on 5 QOL subscales, intrusion levels and marital (dis)satisfaction. Children differed in their emotional and behavioral functioning according to the parents. The externally-recruited group functioned more poorly.

Conclusions: Participants in psycho-oncological studies recruited from different sources should not be considered equal. Authors should describe the samples in detail and specify how different samples are grouped together in analyses in order to see if and to what extent selection bias may exist.

Finding participants is one of the most important steps in research. Different academic fields employ various methods to recruit subjects, ranging from requiring undergraduate students to participate in graduate study projects to placing advertisements in newspapers and from searching municipal registers to polling people over the telephone. Psychosocial research in oncology, however, requires patients to participate. These types of studies use various sources to recruit subjects, including hospital databases and peer support groups. In order to generalize results beyond the sample group, samples need to be of adequate size and be representative of the general population (Bootsma-van der Wiel et al., 2002; Scholle et al., 2000). The source of the participants may color the results of the study, thus affecting the generalizability.

In a university student population, recruitment method was shown to possibly influence the subject's attitude toward participation (Dixon, 1978). In that study, volunteer students were more hostile toward experimentation than students required to participate for course credit or students who were paid. In a multi-center study on schizophrenics, researchers found that patients recruited from clinical settings may not be representative of all schizophrenics (Loughland et al., 2004). Schizophrenia patients recruited through different sources may vary in socio-demographic profile or neurocognitive functioning. People recruited for the control group may also vary widely and may not be as "normal" as experimenters believe (Bunce et al., 2005). In that study, a surprisingly high prevalence of personality disorders was found in a control group sample, which could have led to bias. A study examining recruitment sources for a bipolar disorder case registry found differences between registrants depending on how they were referred (Scholle et al., 2000). People referred through patient support groups or through the Internet tended to be better educated and younger. Respondents' racial background may also differ depending on how they are recruited (McLean & Campbell, 2003). In that study examining complexities in recruitment, different ethnic groups were found to be more or less likely to participate in a study depending on recruitment method. A study comparing recruitment methods in a smoking cessation program found that recruitment method had an affect on motivation to quit (Hoving et al., 2007). A recent study on cognitive functioning in MS patients found significant differences between samples depending on how they were referred to the study (Duqin et al., 2008).

A large number of psychosocial oncology research teams recruit subjects through hospital databases or face-to-face contact with patients undergoing treatment during a certain period. These methods allow researchers to reach a heterogeneous group of patients, which should ensure that the sample is representative of the entire patient population. Studies that target participants through a peer support group or by placing advertisements in newspapers or magazine may inadvertently identify specific groups of

patients. These participants may represent a sub-group of cancer patients who differ from hospital respondents. Volunteers may be attracted to participate in a project because of illness-related variables or may differ socio-demographically from the general cancer patient population (Berglund et al., 1997). In studies that examine family members, it is possible that the spouses or children vary from family members of cancer patients in the general population. The willingness of the family to participate in a study may be due to illness-related variables, but may also be due to relationship variables or factors in the children.

Recruitment in oncological clinical trials has been extensively researched (Wright et al., 2006; Mills et al., 2006; Tournoux et al., 2006). However, to date, little attention has been paid to possible recruitment source bias in psychosocial oncology. It may be underestimated. Since, to our knowledge, no studies have focused on this subject, the nature of this study is exploratory; our hypotheses are that participants of two differently recruited groups differ: (1) in socio-demographic characteristics and cancer-related variables; and (2) in psychosocial functioning.

Methods

Recruitment sources

We conducted a study investigating the psychosocial effects of parental cancer on younger families. According to the research protocol, the first, and larger, group was recruited at the University Medical Center Groningen (UMCG) in the Netherlands ("internally-recruited"). Surgical, medical and radiation oncologists and oncology nurses approached all admitted and outpatient clinic cancer patients meeting inclusion criteria who underwent treatment at the UMCG during a two-year time period and informed them of the study. Patients in the second group approached the research team themselves for information after having heard of the study through newspaper articles and television news reports printed or aired shortly after the study started ("externally-recruited").

Participants in both groups were eligible for inclusion if patients had been diagnosed with cancer one to five years prior to study entry and had children between the ages of 4 and 18 years at time of parent's diagnosis who resided or had frequent contact with the diagnosed parent. A further inclusion criterion was that parent, spouse and child(ren) needed to be fluent in Dutch. The patient and at least one child were required to participate for the family to be included; spouse participation was not mandatory for the family's inclusion.

The physicians and nurses offered written information to all eligible patients and spouses in the internal group. Children were provided with an adapted information

brochure. Each family member provided informed consent separately, in accordance with regulations of the Medical Ethical Committee of the UMCG. After informed consent was obtained, researchers mailed packets with questionnaires and pre-paid return envelopes to each family member. The external group received verbal information from the researchers. Written information over the study, informed consent forms for each family member, questionnaires and pre-paid return envelopes were mailed to each person separately. Family members in both groups were instructed to fill in questionnaires independently of each other.

Instruments

Demographic data were obtained on: age, gender, level of education, length of relationship, and number of family members. Education level was measured on a seven-point scale from (1) elementary school only to (7) university degree. Cancer patients also provided information on disease and treatment: when diagnosed, tumor site, type of treatment, complications as a result of treatment, and cancer recurrence.

Quality of life (QoL) was measured with the Dutch translation of the RAND-36 (van der Zee & Sanderman, 1993), a shortened version of the RAND Health Survey. QoL status is measured on eight sub-scales: physical functioning (10 items), social functioning (2 items), role limitations due to physical problems (4 items), role limitations due to emotional problems (3 items), mental health (5 items), vitality (4 items), bodily pain (2 items), and general health perception (5 items). Scores on sub-scales can range from 0-100, with higher scores indicating better functioning. The RAND-36 has been shown to be reliable and valid by a number of studies (McHorney et al., 1993; van der Zee & Sanderman, 1993). Cronbach's alphas in this study on the 8 sub-scales ranged between .72-.90 and .78-.90 for patients and spouses, respectively.

The Maudsley Marital Questionnaire-Satisfaction was used to assess (dis)satisfaction in the marriage. Higher scores (range: 0-80) denote more marital distress. This self-report questionnaire is widely used, with high reliability and validity (Arrindell et al., 1983; Arrindell et al., 1983; Hoekstra-Weebers et al., 1998). In this study, alphas were high: .98 and .94 for patients and spouses, respectively.

To assess the emotional and behavioral functioning of the children, both parents were asked to complete the Child Behavior Checklist (CBCL) (Achenbach, 1991a; Verhulst et al., 1996a). In addition, adolescents completed the Youth Self Report (YSR), designed for children 11-18 (Achenbach, 1991b; Verhulst et al., 1996b; Verhulst et al., 1996b). The CBCL and YSR consist respectively, of 120 and 102 items. In this study, the internalizing, externalizing and total problem scales were used. Higher scores denote more problems. The internalizing scale reflects the children's internal mental state, measuring withdrawal,

somatic complaints and anxiety/depression. The externalizing scale represents socially unacceptable behavior such as delinquency and aggressiveness. The total problem scale reflects the total score derived from the sum of all the scales: internalizing, externalizing, thought, social, attention and other problems. The reliability and validity of the CBCL/YSR has been supported in a number of studies. Cronbach's alphas in this study ranged from .84-.94 for reports from patients, spouses and adolescents on the internalizing, externalizing and total problem scales.

Both parents and children filled in the Impact of Event Scale (Horowitz et al., 1979), a 15-item questionnaire measuring psychological stress reactions after a major life event. It measures two categories of responses: intrusive experiences (7 items, range 0-35), and avoidance of thoughts and images associated with an event (8 items, range 0-40). The sum of these is the total score, which can range from 0-75. Patients with scores ≥26 points are considered by the Dutch version of the IES to have clinically-elevated distress symptoms. The IES has been validated in a number of studies (Brom & Kleber, 1985; Sundin & Horowitz, 2003). In this study, Cronbach's alphas were high, ranging for the subscales and total score between .80-.89, .93-.96 and .88-.95 for patients, spouses and adolescents, respectively.

Statistical Analysis

Differences in demographics between the two groups were analyzed using independent-samples t-tests and Chi-square tests. Independent-samples t-tests and ANOVAs were used to analyze group differences on QoL, stress response symptoms, marital satisfaction, and behavioral and emotional problems in the children. MANOVAs controlling for socio-demographic and illness-related variables found to differ between the two groups were performed to analyze differences between groups in order to determine whether group differences in functioning remained.

Results

Participants

Two hundred nine of the 476 eligible families who were approached agreed to participate (44%). No significant differences were found between participating and non-participating families with regard to patient's gender, type of cancer and time since diagnosis. Reasons given for why families did not participate varied: 22% named the parents as the reason not to take part (e.g., having already "moved on" or being too emotionally distressed), 20% said that the children were the primary factor (e.g., not interested or not informed by parents about the illness), 25% gave a variety of explanations (ranging from other illness in the family to business), and 33% did not specify why.

One hundred and sixteen eligible families approached the research team, of which 91 families participated (response rate 78%). No information regarding socio-demographic, illness-related variables or reason for not participating was available from non-participants.

For participating families, data analysis was conducted on families where the patient and at least one child returned questionnaires. This resulted in a total sample of 207 internally-recruited and 89 externally-recruited patients, with 165 and 62 spouses and 378 and 186 children, respectively. Both sample groups consisted predominantly of female patients – internally recruited: 81% (n=167); externally recruited: 74% (n=66). Demographic information is summarized in Table 1. Both patient groups were heterogeneous in type of cancer. Patients in the internal and external groups, respectively, were diagnosed with the following types of cancer: breast (54%, n=112; 61%, n=54), gynecological (11%, n=24; 1%, n=1), dermatological (9%, n=19; 2%, n=2), hematological (8%, n=16; 14%, n=12), soft tissue/bone (5% internal only, n=10), urological (5%, n=10; 5%, n=4), head/neck (4%, n=8; 2%, n=2), gastroenterological (2% n=4; 8%, n=7) and central nervous system (2%, n=4; 8%, n=7). In this study, we grouped treatments into two categories based on the clinical expectation that surgical treatment alone (non-intense) would be less distressing to the family because of less time away from home and fewer visible side effects (internal: n=30, 15%; external: n=9, 10%). Other single-modal (chemotherapy, radiotherapy) and multi-modal treatments (combination of: surgery, chemotherapy, radiotherapy, hormone or immunotherapy) were defined as intense (internal: n=176, 85%; external: n=79, 90%).

Differences in group demographics and illness-related variables

The response rates of the two groups varied significantly (X^2=44.5, p<.001); a greater percentage of families in the internal group declined to participate. Recruitment source did not result in differences in gender or age of patient or spouse, or in number of family members (Table 1). Significant differences in demographics were found between the groups on the following aspects. Both patients and spouses in the external group were more highly educated. Internal couples were married/co-habitating longer than external couples. Children in the internal families were older on average than those in the external families.

With regard to illness-related variables, the two groups as a whole differed significantly in type of cancer the patient was diagnosed with (X^2=28.2, p<.001). The internal group included a significantly higher percentage of patients with gynecological (X^2=8.33, p=.004), dermatological (X^2=4.91, p=.027), and soft tissue/bone tumors (X^2=4.91, p=.027), whereas the external group included a significantly higher percentage of patients

with gastroenterological tumors (X^2=4.75, p=.029) and cancer in the central nervous system (X^2=4.75, p=.029). Additionally, mean time since diagnosis was longer in the external group. External patients more often had a recurrence. No differences were found between the two groups with regard to intensity of treatment or percentage of patients who developed treatment-related complications (such as infection).

Table 1 Demographics

	Internally-recruited		Externally-recruited		Significant differences	p
Mean age in years (SD) patient	44.9	(5.3)	44.3	(5.7)		
(range)	(32.8 – 57.8)		(31.3 – 65.6)			
spouse	45.8	(6.3)	44.6	(5.2)		
(range)	(29.1 – 59.0)		(29.1 – 54.8)			
Gender of patients N *(percentage)*						
Female	168	(81.2)	66	(74.2)	-	-
Male	39	(18.8)	23	(25.8)	-	-
Gender of spouses N *(percentage)*						
Female	37	(22.4)	22	(35.5)	-	-
Male	128	(77.6)	40	(64.5)	-	-
Mean length of relationship in years (SD)	21.2	(6.7)	19.3	(6.5)	t = 2.02	.044
Number of single-parent families	12		19		X^2 = 16.4	.000
Mean education level -patient (SD)						
range 1-7	3.9	(1.6)	4.6	(1.6)	t =-3.81	.000
spouse (SD)						
range 1-7	3.9	(1.8)	4.6	(1.7)	t =-2.54	.012
Mean years since diagnosis (SD)						
range 0.5 – 5.4	2.7	(1.2)	2.3	(1.1)	t = 3.33	.001
Cases with patient complications N *(%)*	53	(25.6)	32	(35.2)	-	-
Cases with patient relapse N *(%)*	40	(19.3)	41	(45.3)	X^2 = 20.9	.000
Mean number of children per couple						
range = 1-6	2.3		2.3		-	-
Mean age of children in years	14.3	(4.8)	12.5	(4.2)	t = 3.15	.002
Type of treatment N *(percentage)*						
Non-intense	31	(15)	9	(10)	-	-
Intense	176	(85)	80	(90)	-	-
No treatment data	1		1			

Only significant differences are listed.

Patient functioning

Patient QoL differed significantly on all 8 subscales, with external patients functioning more poorly (Table 2). With regard to stress response symptoms, external patients reported more intrusion than internal and had a higher total score. Additionally, 55% (n=49) of external patients reported clinically-elevated distress levels, compared with 32% (n=66) of internal patients (X^2=9.06, p=.003). No differences were found with regard to marital satisfaction.

As mentioned above, significant differences were found on socio-demographic and illness-related variables. After controlling for these, all differences in patients' functioning remained significant.

Spouse functioning

The two groups differed significantly in QoL on 5 of the 8 subscales (Table 2). External spouses functioned more poorly than internal spouses in: social functioning, role limitations due to emotional problems, mental health, vitality and general health perception. Additionally, external spouses reported more intrusive experiences. The percentage of spouses with clinically-elevated distress levels was comparable: 42% (n=69) of internal spouses and 38% (n=24) of external spouses. Internal spouses were more satisfied with their marriage than external spouses.

After analyses controlling for differences in socio-demographic and illness-related variables were performed, two changes were found. The avoidance and total scores of the IES became significant ($F=6.45$, $p<.001$; $F=6.31$, $p<.001$).

Child functioning

External patients and spouses felt their children were experiencing more emotional and behavioral problems than internal patients and spouses as reflected by the children's total problem, internalizing and externalizing scores. A comparison of adolescent self-reports showed no significant between-group differences in emotional and behavioral problems or intrusion, avoidance and total stress response symptoms (Table 3).

Table 2 Descriptive analysis of Patients' and Spouses' Functioning and Comparisons Between Groups

	Internally-recruited		Externally-recruited		T score for group
	M	(SD)	M	(SD)	differences
Patient					
RAND-36					
Physical functioning	76.5	(21.1)	68.9	(23.8)	2.66**
Social functioning	76.4	(25.1)	62.1	(25.2)	4.49***
Role limitations - physical	64.6	(41.3)	33.4	(40.6)	5.99***
Role limitations - emotional	78.6	(35.9)	56.9	(44.4)	4.06***
Mental health	72.9	(16.5)	64.8	(16.9)	3.84***
Vitality	58.3	(21.5)	48.5	(19.7)	3.67***
Pain	81.1	(22.0)	68.0	(26.4)	4.39***
General health perception	65.0	(22.4)	50.2	(24.8)	5.04***
IES – Intrusion	10.3	(7.9)	14.8	(8.2)	-4.49***
IES - Avoidance	8.4	(8.1)	9.8	(8.2)	-1.35
IES total score	20.4	(16.2)	26.6	(16.0)	-3.03**
Marital satisfaction	13.4	(12.4)	14.3	(14.3)	-0.54
Spouse					
RAND-36					
Physical functioning	89.7	(16.5)	91.2	(12.8)	-0.64
Social functioning	83.2	(23.1)	74.8	(22.8)	2.45*
Role limitations - physical	82.6	(33.5)	76.2	(37.4)	1.23
Role limitations - emotional	86.6	(30.2)	67.7	(40.9)	3.30***
Mental health	77.2	(15.8)	68.8	(18.9)	3.37***
Vitality	67.9	(18.6)	59.4	(19.0)	3.04**
Pain	87.2	(18.9)	82.9	(22.9)	1.44
General health perception	75.2	(17.9)	69.4	(19.9)	2.13*
IES – Intrusion	10.5	(7.9)	13.3	(7.9)	-2.42**
IES - Avoidance	7.3	(7.2)	7.3	(7.1)	-0.05
IES total score	19.0	(15.3)	22.7	(14.6)	-1.66
Marital satisfaction	11.8	(9.7)	15.9	(10.9)	-2.74**

Significant p-values are designated by: * p<.05, ** p<.01, *** p<.001.

Table 3 Descriptive analysis of Patient, Spouse and Adolescent Reports on the CBCL and Comparisons Between Groups

	Internally-recruited		Externally-recruited		T score for group differences
	M	(SD)	M	(SD)	
Patient reports					
CBCL total	19.8	(16.2)	25.2	(19.0)	-3.64***
CBCL internalizing	6.7	(6.4)	8.4	(7.1)	-2.92**
CBCL externalizing	6.4	(5.9)	7.7	(7.8)	-2.10*
Spouse reports					
CBCL total	15.7	(5.9)	21.3	(16.9)	-3.28***
CBCL internalizing	4.9	(13.9)	6.9	(5.9)	-3.39***
CBCL externalizing	5.3	(5.3)	6.9	(6.5)	-2.31*
Adolescent reports					
YSR total score	37.3	(20.4)	39.6	(21.5)	-1.05
YSR internalizing	12.2	(9.1)	12.6	(9.4)	-0.48
YSR externalizing	10.7	(5.8)	11.5	(6.6)	-1.15
IES – Intrusion	8.5	(8.1)	9.9	(7.8)	-1.47
IES – Avoidance	9.9	(9.0)	11.4	(8.9)	-1.59
IES total score	18.2	(15.7)	20.9	(15.1)	-1.64

Significant p-values are designated by: * p<.05, ** p<.01, *** p<.001.

Discussion

This study examined participants in a psycho-oncology study recruited through two different sources. Patients in the first, and larger group, were directly approached in the hospital during, or in the follow up of, their treatment for cancer. The second group of patients was recruited when they contacted the researchers for information about the study after reading or hearing about it through news media. Our findings show significant differences between families recruited through different channels in their socio-demographic characteristics and in illness-related variables, supporting our first hypothesis. This is in line with results from previous research that recruitment methods can influence the sample. Differences were found between patients, and their spouses and children. External parents were more highly educated, were married/co-habitating for fewer years and had younger children than internal parents. External patients were recruited more shortly after diagnosis than internal patients and were more likely to have had a recurrence. The “newness” of the illness or the stress of a recurrence may have been a reason for the external families’ interest in the study.

Our second hypothesis was also supported. Patients and spouses in the two groups differed from each other in QoL; external patients and spouses reported more problems. External patients reported lower scores on all QoL domains. External spouses reported lower scores than internal spouses on 5 domains. Additionally, the two groups differed in levels of intrusion and total distress; external patients experienced more distress than internal patients. More than half of the external patients were clinically

distressed, compared to one-third of the internal patients. Even when scores were corrected for external patients' higher rate of cancer recurrence, distress levels remained significantly higher. It may be that the stress of the illness was stronger in external families at the time of recruitment and that this was a reason for their interest in the study. They may have actively been reaching out for contact with other families or with supportive care professionals, while the families in the internal group were asked during a routine visit with the specialist. Both groups' reports of marital satisfaction were consistent with those of couples satisfied with their marriage (Arrindell et al., 1983). However, external spouses reported more dissatisfaction than internal spouses. Stress within the relationship may also have motivated external families to reach out to the researchers.

External children had more emotional and behavioral problems than internal children, according to both patient and spouse reports. Our hypothesis that the children would differ is only supported when considering the parents' reports, but not the children's. The adolescents' self-report scores did not differ between groups. The parents made contact with the research team. Another possible reason for their interest in the study may have been the problems they perceived in the children's emotional and behavioral functioning.

Limitations of this study revolve primarily around response rates. Our external group was much smaller than the hospital group. However, the response rate from the external group was high, particularly for questionnaire studies. While the response rate from the hospital group was not very high, our 44% is consistent with questionnaire-based research. However, that less than half of the patients approached agreed to participate may have led to sample bias. It is important to note that all studies have limitations. This study stresses the importance of the influence recruitment source can have on results.

In summary, these findings seem to illustrate that samples recruited through different channels cannot be considered equal. Our two samples differed significantly in levels of distress and quality of life as well as on socio-demographic data. Recruitment strategy may influence the outcome of a study. Researchers may employ multiple recruitment methods to include sufficient numbers of participants for statistical reasons, without considering that source could have an impact on results. In fact, studies have been published that report on results of groups recruited in different ways but analyzed as a whole, even though groups were found to differ (Brain et al., 2006). If multiple recruitment methods are employed, attention must be paid to ensure that samples are comparable so that combining samples for analyses does not compromise results or generalizability (Mezei & Kheifets, 2006).

Patients recruited from different sources may not be equally-representative of the general population of cancer patients or of patients with a specific type of tumor or

those undergoing a specific treatment. Responsible recruitment strategies should try to ensure that samples' characteristics mirror the characteristics of the general population of patients to whom the researchers' results would apply. Researchers should provide a careful explanation of the study group and reflect on possible selection bias.

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